Title:

How do radiation oncology health professionals inform breast cancer patients about the medical and technical aspects of their treatment?

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How do radiation oncology health professionals inform breast cancer patients about the medical and technical aspects of their treatment?

Abstract

Background and Purpose: Radiation therapy patients need information to make treatment decisions, understand treatment and manage side effects. The purpose of this study was to: (1) Identify information about radiation therapy routinely provided to breast cancer patients; (2) Determine which health professionals provide information; (3) Examine whether information is routinely provided at the same time points and (4) Determine whether health professionals and patients place similar importance on specific information.

Materials and Methods: Health professionals in radiation therapy departments in Australia and New Zealand completed self-administered questionnaires. Results were analysed and compared to patient responses from a previous study.

Results: Forty-one of 52 departments participated in this survey. Information provision was inconsistent between departments in terms of how and when information was given. Although the types of information provided to patients appeared to align with patients' needs, health professionals and patients placed different levels of importance on specific information.

Conclusions: A wide range of information is provided to patients. However, the priority given to different information needs and the focus of information provision may not be optimal from the perspectives of patients. Further research needs to be conducted to determine patients' information needs and develop specific information resources tailored to meet these needs.

Key words: Information provision, radiation therapy, breast cancer

Introduction

Patients require information prior to making their decision to receive Radiation Therapy (RT). Although RT has been in use for many years, people are still nervous about receiving treatment and feel concerned about the side effects associated with treatment [1-5].

Sainio and Eriksson [6] reported that it is important to provide patients with enough information, that an appropriate method is used to deliver information, and that the timing of information provision meets patients' individual needs. The method chosen to present information is important, as is the timing of information provision, because patients need to be able to recall the information provided on subsequent occasions and particularly when managing their side effects [7-10]. Several studies have identified that information about RT needs to be provided to patients prior to their treatment and investigated ways of providing information earlier [3, 11, 12].

Individual departments are responsible for ensuring that patients have the information they require. It is essential that patients are adequately informed, because insufficient communication and information provision have been reported to have an effect on patient anxiety and may lead patients to decline treatment [7, 13]. Because there are no standard guidelines for the timing of information provision, it is likely that individual departments vary when they provide certain information. Understanding when cancer patients are most receptive to information is important, because providing information at the most suitable time point could increase patients' level of understanding and recall and decrease anxiety about treatment. Therefore, it is important to identify what types of information patients routinely receive about RT and to evaluate whether patients are satisfied with the information they receive.

Two studies were conducted in Europe to compare information provision between RT departments [14, 15]. Hubert et al. [15] surveyed 290/746 RT departments in Europe to determine the differences in information provision. Participating departments completed a questionnaire and sent information resources to be reviewed. All locations provided verbal information and 56% of departments also provided written documentation. Two percent of departments used videos to assist in informing patients. Ninety-nine percent of departments stated that information was given by the radiation oncologists, in 46% of departments this role was shared with radiation therapists, 11% of departments reported nursing staff involvement and finally, in 15% of departments information provision involved all three disciplines. Almost all written documents (95%) contained general information with a definition of RT, description of rays, machines, procedures, adverse effects and advice. However, Hubert et al. [15] stated that these information sources did not provide adequate information on the cancer or the prognosis and risks associated with the disease.

Hammick et al. [14] conducted a study to identify the information giving procedures commonly used in the United Kingdom (UK). Questionnaires were sent to 63 radiographers and 32 questionnaires were returned (response rate 51%). All departments reported they provided patients with written information about RT and 97% of departments provided information specific to the department as well as generic information from outside agencies. Thirty-eight percent of departments had formal telephone support services available and 86% provided unofficial/informal telephone support services. Although it is encouraging that almost all departments provided information to patients and had provisions for an informal telephone service, the response rate was moderate and selection bias could limit the generalisation of these findings to non-responding centres.

These studies [14, 15] provide insight into information provision for RT patients in selected European countries, but the research has limited application to other parts of the world such as Australasia. It is currently unknown what information patients routinely receive in Australia and New Zealand, which health professionals are involved in providing information or when the information is provided. Health professionals' roles in RT departments may differ between Australasian and European countries and therefore it is likely that information provision in these countries also vary. Additionally, patient demographics in these regions are likely to be different. Previous studies have also failed to determine when patients receive treatment related information in different departments, therefore the current study aims to: (1) Identify the information about RT routinely provided to breast cancer patients; (2) Determine which health professionals are involved in providing information at different time points during the patients' RT; (3) Examine whether the timing of information provision is consistent in different RT departments and (4) Determine whether health professionals and patients place similar levels of importance on specific RT related information.

Theoretical Framework

The Information Behaviour Model proposed by Wilson [16] was used to inform this study. This model provides an understanding of how people behave when they are provided with information and why they choose to seek further information. Wilson proposes that information behaviour arises when a patient perceives they are in need of information. Part of people's information seeking behaviour involves asking other people for information. For example, breast cancer patients ask health professionals for further information or increasingly access the World Wide Web for information relating to their condition. The Information Behaviour Model suggests that information behaviour is dependent on the context of the person's information need, what activates them to gain information,

how they are coping with what is happening, intervening variables (psychological, demographic), risks and rewards involved in seeking the information and self efficacy. People may be active or passive information seekers. Regardless of whether patients are active or passive information seekers they are often provided with set information relating to their disease and the treatment they are receiving. However, the information routinely provided may vary and it is not known whether this information meets the needs of either the active or the passive patient.

Methods

A descriptive questionnaire design was used to address the aims of the study. Participants completed a self-administered questionnaire containing quantitative and qualitative questions which focused on determining what information is routinely provided to breast cancer patients; which health professionals are involved in providing information; whether the timing of information provision is consistent in different departments and how health professionals rank the importance of specific RT related information. Details of the questionnaire development and testing follow.

Questionnaire Development

The researchers (GH and LK) recently conducted qualitative interviews with breast cancer patients during their treatment experience. Results from this work led to the development of two RT specific scales: the 'RT Concerns Scale' and the 'RT Information Needs Scale'. The 'RT Concerns Scale' measures patients' concerns about RT and the 'RT Information Needs Scale' measures patients' information needs at different time points during their treatment. These scales were pilot tested for content validity, internal consistency and test-retest validity with 30 patients (response rate = 30/36 patients (86%)). Both tools were found to have high internal consistency and adequate stability over

time. The ‘RT Information Needs Scale’ had a Cronbach’s alpha of 0.86 [17]. The final scale contains 22 items which require participants to identify how important each item of information is on a nine point Likert-type scale with ‘1’ being not important and ‘9’ being very important.

The researchers adapted the ‘RT Information Needs Scale’ so that it was possible to determine health professionals’ perspectives on the importance of different information about RT and when specific information is provided. The scale used in the current study contained 26 items. Five additional items were added and one item was removed because the instruments were developed over time and the authors felt it was necessary to revise the items before administering it to health professionals. The additional items (identified with an asterisk in Table 4) focused on collecting information about the different sources of information (e.g. written, verbal) and personnel involved so that the researchers could assess methods of communicating information as well. The questionnaire also contained items related to the sources and timing of information provision and allowed participants to provide multiple responses to enable the researchers to determine whether information was repeated on several occasions. Once this questionnaire was compiled, five health professionals assessed it for content validity [18]. The findings presented are based on a comparison of results from the ‘RT Information Needs Scale’, which was used to obtain breast cancer patients’ information preferences and results obtained from health professionals using the adapted version of the scale.

Participants

Private and public RT departments located in Australia and New Zealand were identified and addresses for each department were obtained. Information letters and questionnaires were sent to the Chief Radiation Therapist at each department.

Procedure

Ethical approval was gained from Curtin University of Technology. An information letter was provided with the questionnaire. Completion of the questionnaire indicated informed consent. The questionnaire was posted to 46 RT departments in Australia and six RT departments in New Zealand. Chief Radiation Therapists were instructed to either complete the questionnaire themselves or invite another health professional to complete it. To increase response rate, a reminder was sent to departments who had not responded five weeks after the initial mail out.

Data analysis

All data were entered into SPSS Version 15. Descriptive statistics were used to analyse the data. Data from the 30 breast cancer patients who completed the "RT Information Needs Scale' were then compared with the health professionals' responses to determine whether health professionals' and patients' responses were in agreement about the importance of specific RT related information. Demographic information relating to breast cancer patients who participated in completing this scale has been described previously [17].

During data analysis the researchers also referred to Wilson's Information Behaviour Model to determine whether different information provision practices were likely to meet individual patient's information needs as they changed over time.

Results

A response rate of 79% was achieved, with 41/52 questionnaires being completed by health professionals. Most responses contained less than 5% missing data.

Demographics

Thirty-five (85%) of the 41 respondents were from departments located in Australia and six (15%) of the respondents were from departments located in New Zealand. Thirty-one (76%) of the respondents were from public departments and 10 (24%) were from private departments. Thirty-one (76%) of the respondents were from departments located in metropolitan areas and 10 (24%) were from departments located in rural areas.

Thirty-eight of the 41 respondents who completed the questionnaires were radiation therapists (93%), two were nurses (5%) and one was a radiation oncologist (2%). Of the participating radiation therapists, 33 (87%) had worked for more than six years as a radiation therapist.

Sources and timing of general information relating to RT

The main sources of information provided to patients were written and verbal information. The majority of departments placed an emphasis on providing information at the first three time points. Table 1 demonstrates which sources of information were provided to patients and when written and verbal information was provided.

Information providers

Radiation oncologists, radiation therapists and nurses were involved in providing patient information. Thirty-nine of 41 (95%) departments stated that radiation oncologists were involved in providing

information at the first radiation oncologist appointment. This involvement was less with only 8/41 (20%) departments stating that radiation oncologists also provided information at the planning appointment and 16/41 (39%) departments stating that radiation oncologists provide information during treatment. The radiation therapists' involvement was focused on the three later time periods with only 3/41 (7%) providing information at the first radiation oncologist appointment. In comparison, 40/41 (98%) respondents stated that radiation therapists provide information during the planning appointment, 31/41 (76%) stated that radiation therapists provide information on the first day of treatment and 30/41 (73%) departments stated that radiation therapists provided information during treatment.

Nursing involvement in providing information varied between departments. Five of 41 (12%) departments stated nurses were involved in providing information when the patient first meets the radiation oncologist, 13/41 (32%) stated nurses were involved in providing information during the planning appointment, 18/41 (44%) departments reported that nurses provide information on the first day of treatment and 29/41 (71%) reported nurses provide information during the patient's treatment.

Participants were also asked to describe the roles of radiation therapists and nurses during planning and on the first day of treatment. On both occasions radiation therapists were reported to: provide information, answer questions, provide psychosocial and emotional support, collaborate in a multidisciplinary setting and refer patients to other health professionals when necessary. In departments where nurses were reported to be involved in providing information, nurses took on an active role in providing additional information and support to patients and took an active role in assisting patients to manage their side effects.

Importance of specific information relating to RT

Participating health professionals were asked to rank the importance of 26 specific patient information needs (1=least important to 9=most important). Health professionals reported that most items were very important, with the majority of items being scored between 7 and 9. This finding suggests a ceiling effect and is likely to have occurred because health professionals were reluctant to identify possible patient information needs as less important. Although this ceiling effect occurred it was possible to determine which items health professionals ranked as very important and which items were considered relatively less important (see Table 2).

These rankings were compared to the responses that were obtained when the 'RT Information Needs Scale' was completed by 30 breast cancer patients (Table 3). Table 3 demonstrates that there was much more variation in the patient's responses in comparison to those responses provided by the health professionals.

Comparison of the Top 10 information needs identified by both groups, showed that health professionals ranked seven of the ten items similarly to patients. The remaining three information needs that health professionals considered to be less important, but which were identified in the Top 10 most important items by patients, were related to side effects (i.e. whether lungs will be damaged by treatment, how much breast will be treated and whether radiation will affect the heart).

Timing of information provision

Table 4 provides an analysis of when RT related information is provided to patients. The timing of information for the Top 10 items as ranked by patients is presented, rather than presenting the timing of

information for all items. Most departments provided information on the Top 10 items as ranked by patients; however, the timing of information provision varied between departments. Some departments reported that they repeat information on more than one occasion.

Figure 1 demonstrates when departments provide information about the Top 10 items to patients. As the table shows, not all departments provide information about these items at the first appointment with the radiation oncologist. For example, 14 (34%) departments reported that they do not provide information about taking care of the patient's skin until the first day of treatment, whereas 26 (63%) departments provide this information earlier.

Discussion

This is the first study conducted in Australasia to determine what type of RT specific information is provided to breast cancer patients, methods used to provide information and when information is routinely provided. These aspects of information provision were the focus of this study because previous studies have reported the importance of ensuring that information provision is tailored in these ways to meet the varying information needs of patients and to improve information recall [7, 19].

Previous research conducted in Europe and the UK [14, 15] has documented that RT departments provide verbal information combined with a varying amount of written information. The findings of the current study also demonstrate that a combination of verbal and written information is routinely provided throughout RT departments in Australia and New Zealand. All departments reported that both written and verbal information is provided on at least one occasion during the patient's RT experience. Forty-nine percent of departments also stated that they provide group information sessions for patients

to attend and in 90% of departments patients are able to contact staff by telephone if they require information during their treatment. This finding is similar to research conducted by Hammick et al. [14] who reported that 86% of departments in the UK provide unofficial/informal telephone support services. Further research is required to determine whether the methods chosen to deliver information impact on the patients' ability to recall important information about treatment and related side effects. Use of the Information Behaviour Model in research such as this will provide a foundation for understanding how patient's react to information when it is provided in different ways.

In 1997, Hubert et al. [15] reported that two percent of participating departments in Europe were using videos to assist in informing patients. In contrast, 51% of departments participating in the current study indicated that they provide visual information to patients. The current study also found that 66% of departments have information available for patients on a website. Our results suggest that departments are making use of alternative, electronic sources of information provision that patients can access when they require it, rather than only providing information when the patient comes to the department. To our knowledge, this is the first study to report findings on the prevalence of internet sites relating to specific radiation oncology departments. In summary, the availability of different sources of information seem to match the needs of patients, in that verbal and written information were most commonly provided and these information sources have been reported to be patients' most preferred information sources [20]. Further research is required to determine the extent to which different departments are able to meet patient's individual needs. It may be possible to do this by conducting an audit of written and verbal information that is provided.

Consistent with previous research [15], the current study found that radiation oncologists were actively involved in providing information to patients. However, in contrast to research by Hubert et al. [15] who reported that information provision is shared between radiation oncologists, radiation therapists and nurses in only 15% of departments, this study showed that radiation therapists and nurses were routinely involved in information provision, particularly during the planning appointment, on the first day of treatment and during treatment.

This study provides a comparison between health professionals and patients perspectives on the importance of specific information relating to RT. Our findings indicate that health professionals and patients overall had similar perspectives on the importance of specific topics relating to RT. The following topics were ranked in the Top 10 by both groups: “What side effects they may experience”, “How to take care of their skin”, “What radiation therapy will involve”, “Why they need to receive radiation therapy”, “What will happen after treatment is finished”, “What happens on the first day of treatment” and “Who to contact for more information”. However, there were some differences in which items were recorded in the Top 10 by health professionals’ and patients’ perspectives. For example, health professionals ranked whether the patients’ lungs would be damaged as twelfth most important information item, whereas patients ranked this as third most important. Patients rated information about side effects to their heart as eighth most important, whereas health professionals rated it as eleventh. A possible explanation for these disparities could be, that health professionals know these regions of interest receive minimal radiation dose, thus posing minimal risks of acute or long-term morbidity for patients. Similarly, patients ranked “How much of my breast will be treated” fourth on the list, whereas health professionals ranked this as fifteenth on the list. Health professionals may not realise that patients are unaware how much of their breast will be irradiated. Based on these findings, we

recommend that health professionals keep in mind that patients are likely to place a different level of importance to side effects and therefore tailor information to meet these needs.

Consistent with patients' and health professionals' rankings of "What side effects patients may experience" as a very important information need, information about possible side effects was provided in all 41 departments, but departments provided this information at different time points. Twenty-six of 41 (63%) departments reported that they repeated information about side effects on at least one other occasion. Information about why they need RT was provided during the first appointment with the radiation oncologist in all 41 departments. Information about what RT involves was also provided during the first appointment with the radiation oncologist in 39/41 (95%) departments. This information was repeated during the planning appointment in 20/41 (49%) departments and on the first day of treatment in 19/41 (46%) departments. Patients were also provided with information about how to take care of their skin on all four occasions. Information about treatment completion was provided during treatment in 33/41 (80%) departments; however, it was also provided earlier in 20/41 (49%) of departments.

The above findings can be interpreted using the Information Behaviour Model [16], which proposes that patients are likely to have varying information needs at different times during their RT. Interpretation of this model suggests that health professionals need to focus on tailoring information to meet these needs and keep in mind that patients may be active or passive information seekers and may respond better to one particular source of information (e.g. written information) or information that is provided at a particular time point. The most common time to provide information was at the first appointment with the radiation oncologist. This places a large responsibility on radiation oncologists to

provide patients with all the information they require. Departments need to be aware that there is a risk associated with providing large amounts of information at one time point because patients are more likely to forget information that is provided [8]. It is therefore interesting to note that much of the information that patients ranked as important was repeated following their first appointment with the radiation oncologist. Patients may require this information to be repeated, particularly if they are struggling to cope with their diagnosis [10, 21] and are unfamiliar with RT and how treatment works.

It is likely that information is repeated in many departments because a number of health professionals are involved in providing patients with information and health professionals feel it is important to ensure that patients have the information they require. However, patients may not always benefit from receiving repeated information, particularly if this information is inconsistent or if it is presented in such a way to increase the patients' anxiety. For example, repeated information about side effects may in fact increase patient anxiety because the side effects become a focus for them. However, further research is required to clarify whether this is the case.

Health professionals also need to mindful of how information is communicated, particularly because this study has identified that verbal information is the most common form of information provision used to inform patients. Patient anxiety may be increased if information is presented with a worrying tone (for example: "beware of side effects") in comparison to if information is presented using a reassuring tone (for example: "side effects are usually minimal and can be managed/prevented"). Previous research has identified that cancer patients benefit from effective communication and reassurance about information provided during their treatment [22, 23]. Furthermore, we have reported that radiation therapists play an essential role in communicating with patients and providing them

information, reassurance and emotional comfort [24]. Further research needs to be conducted to determine how RT departments can best tailor and present information to meet patients' information needs and ensure that information provision does not increase patient anxiety.

This study achieved a very high response rate (79%) and thus minimised selection bias. Retrospective analysis of departments who did not respond found that non-respondents were equally distributed between states, public versus private hospitals and metropolitan versus rural locations. This suggests that the results presented are representative of departments in Australia and New Zealand. However, there were some limitations to this study. First, the majority of questionnaires were completed by radiation therapists, although some questions asked about roles of other health professionals involved in information provision. This is a limitation because other professionals may describe their roles differently. Second, because this was a postal questionnaire any responses given were considered definite. It is possible that more reliable data could have been collected if researchers attended each facility and observed information provision in an objective manner, but this was not feasible due to the extra time and additional resources required to carry out such a study. Finally, results on information provision only describe the population under study and may not be applicable to RT departments elsewhere. However, we believe that this study provides valuable findings relating to the differences between the level of importance health professionals and patients place to information given on specific RT related issues.

Conclusion

The current study demonstrates that RT departments in Australia and New Zealand provide patients with a range of specific RT related information at different time points during their treatment.

Information provision in this region varied between departments and is different to the findings of previous studies [14, 15]. The current study found that information provision was routinely shared between radiation oncologists, radiation therapists and nurses and many of the departments had electronic information available for patients. The timing of information provision varied between departments; however, many departments reported that they repeated specific RT related information on several occasions as the patient progressed through their treatment. Although the type of information given seemed to match patients' needs, we found that health professionals and patients placed different levels of importance to specific information about various treatment related issues. Further research needs to be conducted to gain an understanding of patients' preferences for specific information at different time points and to ascertain whether their information needs are currently being met and whether they are able to recall the information provided. Research is currently being conducted by the authors in these areas.

Conflict of Interest statement

There were no conflicting interests for this study.

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Table 1: Sources and timing of information

Written information	**Departments (%)**
First RO appointment	21 (51%)
Planning/simulation	25 (61%)
During treatment	6 (15%)
Verbal information	
First RO appointment	37 (90%)
Planning/simulation	37 (90%)
Day 1 of treatment	38 (93%)
During treatment	33 (80%)
Visual information	21 (51%)
Internet site	27 (66%)
Telephone support	37 (90%)
Tour of the department	15 (37%)
Volunteers	13 (32%)
Group information session	21 (49%)

NB: Categories were not mutually exclusive.

Table 2: Information needs ranked as most important by health professional participants

Item (From Most Important to Least Important)	Mean 1=least important 9=most important	Standard Deviation	Min response	Max response	% participants rated most important (score = 9)
1. What side effects they may experience	8.88	0.33	8	9	88%
2. Why they need to receive radiation therapy	8.80	0.51	7	9	85%
3. What radiation therapy will involve	8.71	0.72	6	9	81%
4. How to take care of their skin	8.68	0.61	7	9	76%
5. How to alter their hygiene routine (e.g. use mild soap, no rubbing with towel, pat dry only, shaving needs etc)*****	8.59	0.63	7	9	66%
6. What will happen after treatment is finished	8.59	0.74	6	9	71%
7. Whether they can keep working during treatment	8.49	0.78	6	9	63%
8. Where they need to go on the first day*****	8.46	0.81	6	9	63%
9. Who to contact if they have concerns about treatment or can't come in for treatment for whatever reason*****	8.44	0.74	7	9	59%
10. What happens on the first day	8.39	0.74	7	9	54%
11. Whether the radiation will effect their heart	8.32	0.91	6	9	56%
12. Whether their lungs will be damaged by treatment	8.29	0.84	6	9	51%
13. Who can provide them with information	8.29	0.90	6	9	56%
14. What happens during the planning appointment	8.29	0.98	6	9	59%
15. How much of their breast will be treated	8.20	1.01	6	9	54%
16. Why treatment staff leave treatment room*****	7.90	1.24	4	9	42%
17. How long planning takes / waiting period before treatment?*	7.88	1.29	3	9	39%
18. What the x-rays that are taken on the treatment machine are used for	7.80	1.23	4	9	39%
19. Why there are cameras and computers in the treatment room and what they are used for	7.66	1.43	3	9	39%
20. Transport that is available	7.63	1.26	5	9	32%
21. Parking	7.59	1.52	5	9	37%
22. The cost of treatment	7.02	2.44	1	9	44%
23. The roles of the different staff in the department	7.00	1.45	4	9	22%
24. The treatment machine	6.93	1.55	3	9	17%
25. How their treatment is planned	6.61	1.36	4	9	12%
26. Other people's experiences of receiving treatment	5.73	1.94	1	9	10%

*** Items not included in the patient questionnaire**

Table 3: Information needs ranked as most important overall by breast cancer patients who had received radiation therapy (n=30 patients)

Item (From Most Important to Least Important)	**Mean** 1=least important 9=most important	**Standard Deviation**	Min response	Max response	**% participants rated most important (score = 9)**
1. What side effects I may experience	8.50	0.96	5	9	67%
2. How to take care of my skin	8.43	0.96	6	9	63%
3. Whether my lungs will be damaged by treatment	8.21	1.60	2	9	63%
4. How much of my breast will be treated	8.17	1.69	1	9	63%
5. What radiation therapy will involve	8.10	1.13	5	9	50%
6. Why I need to receive radiation therapy	8.10	1.54	3	9	67%
7. What will happen after treatment is finished	7.68	1.91	1	9	40%
8. Whether the radiation will effect my heart	7.64	2.44	1	9	57%
9. What happens on the first day	7.31	2.12	2	9	37%
10. Who can provide me with information	7.11	2.22	1	9	37%
11. The radiation oncologist who is treating them*****	7.19	2.33	2	9	43%
12. How my treatment is planned	7.07	2.07	3	9	37%
13. What happens during the planning appointment	6.97	2.04	1	9	30%
14. What the x-rays that are taken on the treatment machine are used for	6.96	2.18	1	9	30%
15. The treatment machine	6.90	2.23	1	9	30%
16. The roles of the different staff in the department	6.66	2.79	1	9	43%
17. Why there are cameras and computers in the treatment room and what they are used for	6.34	2.54	1	9	23%
18. Other people's experiences of receiving treatment	6.00	2.99	1	9	27%
19. The cost of treatment	5.48	3.26	1	9	27%
20. Whether I can keep working during treatment	5.31	3.67	1	9	33%
21. Parking	5.21	3.36	1	9	30%
22. Transport that is available	3.37	3.09	1	9	10%

*** Not included in health professional questionnaire**

Table 4: Timing of information relating to radiation therapy

Note: Top 10 items as ranked by patients. Bold indicates the most common time points.

	Do not provide	On patient request only	First appointment with radiation oncologist	Planning appointment	First day of treatment	During treatment
	N (%)					
1. What side effects they may experience	0	0	31 (76%)	17 (41%)	**32 (78%)**	15 (37%)
2. How to take care of their skin	0	0	13 (32%)	22 (54%)	**33 (80%)**	24 (59%)
3. Whether their lungs will be damaged by treatment	1 (2%)	4 (10%)	**34 (83%)**	8 (20%)	4 (10%)	3 (7%)
4. How much of their breast will be treated	3 (7%)	1 (2%)	**29 (71%)**	14 (34%)	13 (32%)	5 (12%)
5. What radiation therapy will involve	0	0	**39 (95%)**	20 (49%)	19 (46%)	2 (5%)
6. Why they need radiation therapy	0	0	**41 (100%)**	3 (7%)	0	0
7. What will happen after treatment is finished	0	0	14 (34%)	6 (15%)	7 (17%)	**33 (80%)**
8. Whether the radiation will effect their heart	1 (2%)	4 (10%)	**33 (80%)**	10 (24%)	7 (17%)	4 (10%)
9. What happens on the first day of treatment	0	0	6 (15%)	23 (56%)	**29 (71%)**	0
10. Who can provide them with information	0	1 (2%)	**28 (68%)**	23 (56%)	23 (56%)	17 (41%)

Table 5: First Time Information Is Provided

	First appointment with radiation oncologist	Planning appointment	First day of treatment	During treatment	On patient request only	We do not provide	Missing
1. What side effects they may experience	31 (76%)	3 (7%)	7 (17%)	-			
2. How to take care of their skin	13 (32%)	13 (32%)	14 (34%)	1 (2%)			
3. Whether their lungs will be damaged by treatment	34 (83%)	2 (5%)	-	-			
4. How much of their breast will be treated	29 (71%)	6 (15%)	2 (5%)	-	3 (7%)	3 (7%)	2 (5%)
5. What radiation therapy will involve	39 (95%)	2 (5%)	-	-	1 (2%)		
6. Why they need radiation therapy	41 (100%)	-	-	-			
7. What will happen after treatment is finished	14 (34%)	3 (7%)	3 (7%)	21 (51%)			
8. Whether the radiation will effect their heart	33 (80%)	2 (5%)	1 (2%)	-	4 (10%)	1 (2%)	
9. What happens on the first day of treatment	6 (15%)	19 (46%)	16 (39%)	-			
10. Who can provide them with information	28 (68%)	8 (20%)	4 (10%)	-	1 (2%)		

Note: Top 10 items as ranked by patients. For full details of when information is provided to patients for items not listed please contact the authors.